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SHORT PAPER

Initial findings from analysis of data from Child Death Review (CDR) processes in the United States (US) and Canada

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This paper presents initial findings from phase 2 of an international study which aimed to pool knowledge and identify good practice across countries which review all child deaths, or all unexpected deaths, in order to inform learning around prevention. It is based on documentary analysis; data from in-depth individual and joint interviews with 30 key informants in the US (3 in Maryland, 3 in California, 5 in Colorado, 1 in Georgia, 7 in the District of Columbia (DC), 8 in Washington, 2 in Wisconsin; and the director of the National Centre for Child Death Review (NCDR) and 8 in Canada (6 in British Columbia (BC), 2 in Ontario); data from observations of state and local CDR meetings in 5 US states; and data collected at a national meeting attended by 67 state CDR program co-ordinators from the US and Canada.

KEY POINTS

- There is no national coordination in the US or Canada; states and provinces organise their CDR systems in different ways
- 36 US states use the NCDR case reporting system so some national data is available; national data is not available in Canada
- The US Sudden Unexpected Infant Death (SUID) case registry is an excellent example of how CDR data can improve our understanding of why children die and enable us to develop evidence based initiatives to try to prevent deaths
- Useful thematic analyses of CDR data have been undertaken in Canada and the findings of these analyses have been used to inform national policy and prevention initiatives and facilitate practice improvement
- Some CDR teams in the US lack the power, or resources to monitor whether recommendations are being implemented; it may be easier to move from review to action and prevention when review and implementation are regarded as separate functions.

BACKGROUND

Significant proportions of child deaths may be preventableⁱ. Mechanisms for reviewing child deaths vary within and across countries. Some areas review only abuse and neglect deaths; others take a wider public health approach and review all deaths. There is a growing body of evidence on the effectiveness of comprehensive CDR processes – they have contributed significantly to knowledge about child abuse and neglect and led to policies and initiatives that have made a major contribution to keeping children safeⁱⁱ. The UK can learn from initiatives in countries such as the US and Canada.

OVERVIEW OF CDR PROCESSES IN THE US AND CANADA

There are no federal requirements to undertake CDR in the US. Each state is different: 31 states undertake state level review; 35 undertake county level review; 17 states do both; one state does neitherⁱⁱⁱ. Some states have a large number of local teams, for example there are 159 in Georgia. 37 states have mandated state CDR; 7 have no legislation for state CDR; in 7 states legislation permits but does not mandate state CDR. Some states, for example California, have a mandate to review only abuse and neglect deaths but may choose to review other deaths as well. 15 states have mandatory local CDR; 18 states have no legislation for local CDR; 18 states have legislation permitting but not mandating local CDR^{iv}.

*Dr Sharon Vincent was a Research Fellow at the Child Protection Research Centre between 2007 – 2011.

Some states believe legislation is invaluable because it requires agencies to share information; others report that agencies share data anyway so there is no need for legislation. Some people report that legislation protects them from subpoena; others feel this would not hold up in court and believe there are other ways to obtain protection than legislation. Some states feel that legislation gives them a 'bit more of a hammer' when making recommendations while others report that their legislation is out-dated or overly restrictive.

Over time there has been a move away from child welfare or justice agencies leading CDR towards a public health model but social services still co-ordinate CDR in 11 US states and in a small number the function is located in the medical examiner's office. The focus of CDR has expanded over time. While many teams initially reviewed only abuse and neglect cases most now review all deaths up to 18 (DC and Wisconsin review deaths up to 25); 11 states also undertake serious injury reviews. Most states maintain separate internal agency review processes for reviewing deaths of children known to child protective services (CPS).

Funding for CDR in the US is generally unstable. The median income of CDR teams is falling and some states have no funding at all^v. California used to have a state council but are no longer able to fund this. They retain a mandate to collect information under the penal code and fulfil this by giving local CDR teams a small sum of money to input data. Washington had a statewide panel and a robust database of all deaths funded by public health but this has been disbanded. Only 17 of the 30 original local teams now review child deaths and data are no longer statewide. Where dedicated funding is available it tends to come from the federal maternal and child health block grant but some teams are funded through general state revenue funds. Some states have more than one funding source and some have unusual funding structures, for example, Arizona and Nevada receive funding from death certificates and Alabama receive funds from a tobacco settlement.

Most US states do not involve families in CDR and believe it is inappropriate to do so.

There are no federal requirements to undertake CDR in Canada. Each province is different. Most provinces have processes for reviewing deaths of children known to the child welfare system but more comprehensive CDR processes only exist in 3 provinces. In BC and Ontario

CDR is undertaken by a team within the Coroner's office at provincial, not local level. The BC CDR Unit has a legislative mandate to review the deaths of all children aged 18 and under; there is a separate review system within the Advocate's office for reviewing the deaths of children in the child welfare system. In Ontario all deaths of children under 5 and of children with a file open to a Children's Aid Society at the time of death, or within 12 months, are reviewed; a paediatric death review committee reviews medically complex deaths or cases where there are concerns regarding medical care. BC always involve families in CDR and have done much to strengthen working relationships with Aboriginal families. Families are not involved in Ontario. Both provinces have dedicated funding for CDR but budgets have been cut substantially in BC.

DATA

Variation across states and provinces makes it difficult to obtain reliable national data in the US and Canada. However, 36 US states use a standardised web based case reporting system developed by the NCDR who are custodians of a national database with extensive information on 88,000 child deaths. The system was designed to inform improvements in child safety and prevent deaths and NCDR use the data to inform federal agencies and influence national policy. The data are, however, limited. Comparison across states can be problematic because there are so many different systems in the US. Data quality is variable because teams answer questions in the datasheet in different ways and some questions are subjective, for example, was this death preventable? Missing data is common because teams do not always answer the harder questions^{vi}. There can also be a significant time lag between a child dying, a review being undertaken and data being entered.

The NCDR case reporting system is being used by the US Centers for Disease Control and Prevention (CDC) funded SUID case registry pilot in 7 states. Most SUIDs are of previously healthy infants. A high proportion of these deaths may be preventable but death certificates contain very little information about the context of the death, for example, whether co-sleeping was a factor. CDR data provides more information about SUIDs. The SUID case registry is a state population based surveillance system that builds on CDR data. SUID specific variables around the sleep environment have been added to the data that is normally recorded by CDR teams to establish what was going on in the child's

environment at the time of death. For example, there are questions about mothers' pregnancies and whether they smoked; there are also infant health questions relating to the 72 hours before death such as whether children were sick or had had immunisations. A number of systems variables have also been added. Data collection begins at the death scene so death scene investigation and recording, including witness statements, are being improved and scene re-enactments undertaken. CDR teams are also being given increased access to autopsy information. Improved national reporting will enable better identification of SUIDs, determine which factors in the sleep environment contribute to SUIDs and enable better identification of high risk groups to inform interventions, affect policy and practice change and prevent deaths. There is evidence that the SUID pilot process is leading to improvement in the quality of all reviews not just SUID cases. One CDR expert has suggested that there should be a similar pilot looking at abuse and neglect deaths since only CDR teams can count such deaths accurately.

California collect data on child abuse fatalities in a different way from other US states. They have worked with the military and SLNI to try to better define child abuse and neglect deaths. Their data is, therefore, more accurate than states which rely on child welfare or CDR team data. They have developed a new reporting system called SB 39.

THEMATIC ANALYSIS

BC and Ontario annually review their CDR data and use the findings from this analysis to identify particular issues or themes that require further investigation through aggregate reviews. BC have convened CDR panels to examine the alcohol related deaths of Aboriginal youths, child and youth suicide deaths, drowning deaths, sudden infant deaths and child pedestrian deaths. Panels review the facts and circumstances of deaths and provide advice to the Chief Coroner that may impact public health and safety and the prevention of deaths. Reviews always include the family's perspective and a review of best practices from other jurisdictions.

Drowning and fire deaths have been reviewed in Ontario. The fire death review found that children from families known to child protection services (CPS) were 32 times more likely to die in fires. It also found that fire play by preschool children was the number one cause of fire death. It was concluded that there was a need to redirect intervention at high risk families – those known to CPS and families with preschool children. It recommended

that primary care physicians should routinely educate families during parent/child health examinations. They now educate smokers to stop smoking and keep matches and lighters out of the way; inquire into fire setting and fire play behaviour; and if necessary refer children for counselling or psychiatry. Family physicians were felt to be the most appropriate professionals to educate families with child protection involvement about child safety because they had the most trusting relationships with families.

DEMONSTRATING IMPACT

Demonstrating that CDR is making an impact can be difficult. The SUDI project is having a demonstrable impact nationally and will be an important model to replicate. At state and local level legislative mandates often require teams to report on findings and make recommendations to policy makers but CDR teams also need to track their recommendations to monitor whether they are making a difference. 18 US states have legislation requiring them to produce annual reports. A number of teams have collated 3 to 5, or in Delaware 10 years of data to report on trends over time. They feel these are more interesting and less repetitive than single year reports and more useful to legislators. Only 7 US states require a response to their recommendations^{vii}. Following the death of Logan Meyer Maine developed a data base to track all the child welfare recommendations from CDRs and can now monitor progress made since 1997. Ontario require a response to their recommendations within a certain timeframe and include responses in their annual report. BC also monitor recommendations and report on progress in annual reports; they also award gold stars to acknowledge successful prevention initiatives. For example, Vancouver Island Health Authority was awarded a gold star for 'Baby's own bed' an initiative to promote culturally appropriate messaging about safe sleep.

Some CDR teams do not have the resources to track recommendations. Some, therefore, prioritise recommendations or focus on a small number, for example, Colorado has 'top' recommendations. In some states or provinces in the US and Canada the review team do not have responsibility for implementing recommendations because the review process is distinct from the implementation process. For example, in Wisconsin an advisory committee considers aggregate data and makes recommendations for legislative change. In Alaska an advisory board meets quarterly and acts on one recommendation at a time (the most recent was

winter safety). Baltimore has a separate community action team and neighbourhood action team with representatives from families and neighbourhood organisations. In some states Safekids coalitions take recommendations forward.

State and local CDR teams are able to provide examples of how CDR has led to successful prevention programs. For example, in Sacramento in California a comprehensive home visiting programme 'Birth and Beyond' came out of the CDR team's recommendations. The CDR team believe that Birth and Beyond contributed to a reduction in the number of child abuse and neglect (CAN) homicides in Sacramento. Funding for this program has now been cut and the team believe this is why there has been an increase in the number of CAN homicides.

Despite its size the US has made significant progress in sharing good practice across states. The Maternal and Child Health Bureau fund an annual meeting of state co-ordinators and the federally funded NCDR has an excellent website which includes best practice tools. A South East coalition of 14 states meets to share good practice and there are site visits across teams with similar child death profiles, for example, Atlanta and Detroit.

IMPLICATIONS FOR THE UK

The UK can learn from the excellent thematic reviews that have been undertaken in Canada.

CDR is firmly rooted in the US and data collection is, therefore, further advanced than here. However, the UK has a potential advantage over the US because our system is better coordinated with LSCBs all reviewing deaths in the same way. We could learn much about how to improve the quality of our national data from examination of the NCDR case reporting system and abuse and neglect reporting system in California. The SUDI case registry is an excellent example of how CDR can contribute to the knowledge base about child deaths and make a major contribution to keeping children safe and should be replicated for abuse and neglect deaths.

The UK can learn much from prevention initiatives in the US and Canada but funding cuts are threatening the effectiveness of CDR in some parts of the US and we need to ensure this is not replicated here. We should also learn from the US and develop robust ways of sharing good practice.

ABOUT THE PROJECT

In 2010 I was awarded a Leverhulme Research Fellowship to enable me to conduct an international study of CDR processes. The study considered what data is collected on child deaths in the UK, Australia, New Zealand and North America, what the data tells us about the main risk factors, how child deaths are reviewed, whether the different approaches to CDR in these countries are congruent with a public health approach and whether review has been effective in reducing child deaths. A case study approach was adopted comprising analysis of documents such as international, national and local child homicide and fatality statistics and annual reports of CDR teams; it also included semi-structured interviews with key informants including policy makers, members of CDR teams, academics, and practitioners. The study was undertaken in 3 phases. The fellowship provided funding for Phases 1 and 2 which comprised fieldwork and analysis in Australia, New Zealand, the US and Canada. Phase 3 which comprises fieldwork and analysis in the UK has yet to be undertaken.

Further information about this study can be obtained from
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ABOUT THE CENTRE

The **Child Protection Research Centre** was set up in 2007 as a unique collaboration between The University of Edinburgh and the NSPCC. Our research is designed to generate a more integrated and deeper understanding of child protection in the UK and internationally, in order to strengthen policy and practice. The Centre is committed to pursuing a programme of knowledge exchange that makes a positive impact, including fostering dialogue between policy makers, practitioners and academia.

Dr Sharon Vincent was Research Fellow at the Centre between 2007 and 2012. The Centre was previously known as The University of Edinburgh/NSPCC Centre for UK-wide Learning in Child Protection (CLiCP). This name features of publications produced between 2007-2011.

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ⁱ Vincent (2010) Learning from Child Deaths and Serious Abuse, Edinburgh, Dunedin.

ⁱⁱ Vincent 2010 *ibid*; Injury Prevention February 2011 Vol 17, Supplement 1.

ⁱⁱⁱ NCDR The Status of Child death Review in the United States in 2010

^{iv} NCDR *ibid*.

^v NCDR *ibid*.

^{vi} Covington, T (2011) The US National Child Death Review Case Reporting System, Injury Prevention, 17, 1, 134-137.

^{vii} NCDR *ibid*.